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LETTER FROM THE EXECUTIVE DIRECTOR

APRIL 2011

Mystery of Preeclampsia Revealed!

It's hard not to get excited when you read that headline. And then you remember that it's April 1st and you're probably having your leg pulled. Before you consider yourself an "April Fool," consider these other headlines, pulled directly from media sources around the world over the last month or two:

"Faulty gene that causes pre-eclampsia discovered."

"Gene study lifts hopes on pregnancy."

"New gene linked to preeclampsia discovered."

"First genes linked to pre-eclampsia and immune system disorders."

Reasons to get excited? Safe to trust the news source?

Many investigators are using genomics - the study of our genes - to discover areas of our genome responsible for specific pregnancy functions that seem to go awry in preeclamptic women. The problem with headlines that suggest "the" gene has been found is that experts mostly agree that preeclampsia is a multifactorial disease, meaning that preeclampsia may have multiple causes with several different genes responsible for a variety of malfunctions. No single gene causes preeclampsia; more likely it is the confluence of many aberrant genes. Read our article about the [cause of preeclampsia](#) for a better description and let us know what you think.

In other news, not all media headlines are misleading or hyperbolic. *The Wall Street Journal* recently (and accurately) reported the impact of pregnancy on a woman's future health risks in "[Problems in pregnancy signal future health risks](#)." This was an important endorsement of our years of work to educate the public and influence the provision of preventive health care for preeclampsia survivors. If you or somebody you know is a preeclampsia survivor, [print out these guidelines](#) and take them to your health care provider. Make sure s/he is noting your pregnancy history in your health records. It matters.



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Sincerely,



Eleni Tsigas
Executive Director



PROMISE WALK: THREE R's TO MAKING A DIFFERENCE

Register, Raise Funds & Raise Awareness



The countdown to *The Promise Walk for Preeclampsia* continues with teams and individuals scrambling to secure the most donations. This month we celebrate our top three teams: **Scuderia Reyes** (San Diego), **Cooper Landon Barnett** (San Jose), and **Team "Down with BP"** (Chicago), all with over \$1,000 raised so far!

The top three individuals are giving the teams some stiff competition. **Lisa Bloch** (San Jose) has already brought in over \$1,000 and **Sarah Scott** (Raleigh) and **Stephan Pollitt** (San Jose) are already over \$500. With a little over a month to go for some of the walks, turn on the heat!

When you [register for a Promise Walk](#) and raise funds as an individual or as a team, you are rewarded for your efforts with a **Promise Walk ribbon magnet, key chain or hat** as you reach certain fundraising levels, but those rewards can turn into much more "rewarding" prizes when they help you initiate a conversation about the Promise Walk and the Preeclampsia Foundation. Each one of the awareness-raising items encourages questions from people you meet, opens the door to share your personal story or why you are committed to this important cause, and lets other survivors and supporters know that there is an organization changing the lives of mothers and their babies and catalyzing research to find the cause and cure.

[Read More about this year's Promise Walk efforts...](#)

HEARD ON THE HILL

Maternal Health Bill Seeks Care Improvements



Despite spending more money than any other country on health care, the United States has a higher maternal mortality rate than 40 other

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countries, with more than two women dying every day in the United States from pregnancy-related conditions, such as preeclampsia and eclampsia. "Near misses" are also important to quantify and understand. According to a 2010 report released by Amnesty International (AI), nearly 65,000 women almost died from pregnancy-related conditions in 2004 and 2005. Approximately 16% of the reported maternal deaths were due to preeclampsia and eclampsia. The AI report also indicated that as alarming as these figures are, they "probably significantly understate" the actual numbers because of the limitation of maternal health statistics currently being captured.

On March 3, 2011, the Maternal Health Accountability Act (H.R. 894) was introduced by Rep. John Conyers (D-Mich) to work toward establishing an accurate picture of maternal mortality in the United States. The bill seeks to provide funds to states to establish Maternal Mortality Review Committees that will allow states to accurately report and understand the causes and effects of maternal mortality. HR 894 also directs the Secretary of Health and Human Services (HHS) to organize a national workshop with a goal of developing uniform definitions of severe maternal morbidity in the United States and work to eliminate disparities in maternal health outcomes. A more formal reporting and analysis process should lead to improvement in care evaluation, the development of guidelines and the improvement of research through the data collected.

It's important for patient advocacy organizations like the Preeclampsia Foundation to be part of the planning process in partnership with care providers and other stakeholders. In the coming weeks, we will be engaging Rep. Conyers and other co-sponsors of the bill to offer our recommendations about how the legislation can build on and seek to expand state-based initiatives already in place.

[Read more details about HR 894...](#)

DEALING WITH PREECLAMPSIA

Pregnant Again After Preeclampsia?

If you've had a hypertensive disorder of pregnancy in a prior pregnancy, dealing with a subsequent pregnancy can be emotionally difficult. Preparation is the key to a positive emotional and physical experience, with the best possible outcome.

Learn: Ask your health care professional for a write-up of your prior pregnancy. Focus on what happened to your body and how your symptoms manifested. Have a preconception check up with a specialist who can test for underlying conditions such as clotting disorders or chronic hypertension. The more you know about what happened to you, the more you can be aware of signs and symptoms should they repeat themselves. Read about all the various signs and symptoms in case preeclampsia presents itself again, but perhaps differently.

Rally Your Support Group: Every pregnancy ends with Mom needing additional help. Add a pregnancy complication and you may wish for a small army at your disposal. Line up the folks you know you can count on and trust to fulfill certain duties while you cannot and keep them informed of your health status. Not only will they be better equipped to help you, but sometimes it takes another perspective to see things - like changes in our appearance that may signal key symptoms.

[Read More Tips on Preparing for Preeclampsia...](#)

VOLUNTEER OF THE MONTH PROFILE

Autumn Spear: Promise Walk Beat Editor

What was your experience with preeclampsia?

At 21 weeks into my first pregnancy with our daughter Sydney, I developed severe preeclampsia and HELLP syndrome and had no idea what was happening. I spent a week in the hospital trying to sort out what was happening at such an early stage in my pregnancy when preeclampsia is not typically seen. When my symptoms worsened, I was transferred to a high risk hospital and forced to deliver our stillborn daughter. It was a horrible and frightening experience. With the help of a maternal-fetal medicine specialist, we were able to deliver a healthy baby boy a year later though I still developed preeclampsia again at 36 weeks.



Why do you volunteer for the Preeclampsia Foundation? What volunteer positions have you held?

I served as co-chair for Saving Grace in Seattle in 2010 and am now the Promise Walk Beat Editor. I volunteer because when I lost the most important thing in my life and had just gone through the most tragic event of my life, I was lost and scared and wanted answers. The Preeclampsia Foundation's website and message boards provided not only answers but hope and friendship. I found my way to the Promise Walk in San Diego two months after we lost Sydney and was so comforted by the embrace I felt from the PF community and the other women whose stories mirrored mine. I volunteer to give back and be that person for other women who so tragically have to go through the same experience.

[Read More About Autumn Spear's Involvement...](#)

PROMISE FOR TOMORROW

Informing Others Without Fright

Have you ever been standing in the checkout line and had the urge to tell the pregnant woman in front of you about preeclampsia? If you follow these three easy steps, you just might be able to help save a life!

Initially, approach the conversation with a flattering question, "Congratulations, when are you due?" then lead in with "Is this your first baby?" Most women love to dote on the impending arrival of their baby. Humor is also a great approach. For example, "You look incredible! When I was in my last trimester I was so swollen from preeclampsia, I couldn't see my own feet." Little conversational volleys get the dialogue flowing in a comfortable direction.

The second step is to transition into your story. When you share a snippet of your life or pregnancy experience, it can provide a perfect opportunity to explain preeclampsia. Newsletter writer Laura Dale transitions into her story by saying, "I have a healthy 3 year old son. He's our miracle baby, as he was born premature as a result of being induced early due to preeclampsia," and says she has never had a mom walk away at this point in the exchange. This is the hook, line, and sinker portion of the conversation.

Many times, women will say, "What is preeclampsia, I have never heard of it?" or "My doctor mentioned preeclampsia; I didn't realize it was so dangerous?" This is your golden opportunity to begin step three of the conversation: share the information, facts and direct them to the Preeclampsia Foundation website for additional help. By sharing this valuable information you are making a promise for tomorrow - a promise for healthier outcomes for other mothers and babies.

MEMBERS MAKING A DIFFERENCE

Spring Toward Fresh Fundraising

Spring is near, and many areas of the country are ready to shake off the snow and welcome the warmer weather. Outdoor gatherings such as garden tours, Easter parades, arts festivals and baby item sales seem to appear everywhere you go. Could these be opportunities in your community for distributing preeclampsia materials at an information stand? Email [Johanna Aiken](#), Director of Patient Education to learn more about distributing brochures and other patient education materials at your local events.



There are also a variety of fresh ways you can use the season to benefit the Foundation through fundraising: check out the brand new "[Top Ten Spring Fundraising Ideas](#)" for some inspiration. Visit the [Events page](#) to see how members in Texas, Iowa, and California have already committed to using spring to refresh their volunteer efforts and inspire local group development. Promise Walk teams are also gearing up for their area walks

by hosting sports tournaments, sales, and dinner nights to boost local participation and contributions.

Spring Break can also be a great time for students to get involved in making a difference in their local community. Candy sales, flower sales, bicycle or motorcycle rides can rally support for critical awareness and fundraising, and is a great way to get those volunteer hours! Have an idea for a fundraising and awareness project or event in your area? Contact Director of Local Fundraising [Dawn Detweiler](#) for support and guidelines.

[Forward email](#)



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